"Listening and Learning From Transition-Age Youth and Their Families"

A Project of the
Maryland Coalition of Families
for Children's Mental Health

Maryland Coalition of Families for Children's Mental Health

August 2006

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Special thanks to all of the youth and families who participated in the focus groups and shared their stories, challenges, hopes and dreams.

DEDICATION

This report is dedicated to all transition-age youth with mental health needs and their families. May you find this report is a source of strength and hope for the future.

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Maryland Coalition of Families for Children's Mental Health

LISTENING AND LEARNING FROM FAMILIES AND TRANSITION-AGE YOUTH

"Transition is a perilous journey." – A Father

***"I told my mom, I'm never going to leave, I'm gonna live under my bed until I die, because, I'm not kidding, it's scary out there."* – A Youth**

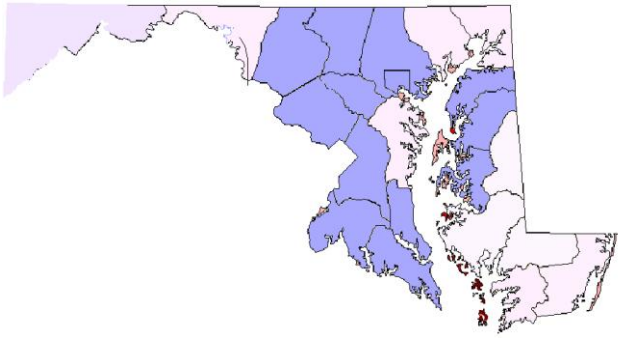
Background

As a result of numerous desperate calls from families regarding their children leaving school or turning 18 years of age, the Coalition noted the lack of services and supports for transition-age youth between the ages of 17-24 years. The Coalition developed a project designed to reach out to families and transition-age youth and learn from their experiences.

Listening and Learning from Families and Transition-age youth was launched in spring 2006 and consisted of focus groups conducted at six locations around the state. At four locations, the youth and parents or caregivers were divided into separate groups and asked similar questions to get their unique perspectives on the issues. At the other two locations the parents and youth groups were combined. To ensure consistency, Coalition staff facilitated each group and used the same format and questions each time. Groups were conducted in urban, rural and suburban areas and included a mixture of socio-economic and racial participants.

The report represents input from 32 youth and 34 family members or caregivers who participated in the focus groups. An additional one youth and six family members responded to a survey that was e-mailed throughout the state. Responses represent 11 counties and Baltimore City or 50% of the jurisdictions in the state.

Figure 1. Shaded area indicates jurisdictions represented by families, caregivers and youth in focus groups and surveys.



Participants

Participants were asked to complete data collection sheets at the end of each group. Those who responded to the survey also completed the data sheets. The following summarizes the profile of the participants:

- Ages ranged from 15-25 years with an average age of 18 years
- 58% were male and 42% female
- 37% had been in residential treatment. The length of stay ranged from 6 months to 11½ years with a 4 year average length of stay
- 60% had graduated from school or expected to graduate
- Approximately 15% had dropped out of school
- 65% of the youth had been hospitalized for psychiatric treatment an average of 6 times
- 11% were presently working; 65% needed employment
- 65%% of the youth were still living with their families
- 8% were homeless

Detailed data about the participants is contained in the Appendix to this report.

SUMMARY OF FOCUS GROUPS AND SURVEYS

During the focus groups, youth and families both agreed that transition, the period from roughly 16– 24 years, is an especially difficult time for youth with mental health needs. Emotional or behavioral difficulties impair the very abilities necessary for a successful transition to adulthood.[i] Parents, caregivers and youth often expressed ***fear*** about what lies ahead. Families had concerns about whether their children could "make it" without extensive support. Often the support was not available and so families continued to provide all of the supports – housing, finding or creating jobs for their children, providing transportation, assisting with money management and arranging social activities.

Transition is a time when the structure and predictability of school is over and decisions must be made about housing, employment or college. Applications for benefits such as Supplemental Security Insurance (SSI) or Medical Assistance (MA) must be submitted. Families and young adults must learn a new cast of agencies and players such as the Division of Rehabilitation Services (DORS). Families stated they did not know where to find information or guidance about how to navigate the new adult service systems. Frequently, youth didn't want any part of programs, since they felt stigmatized by them.

Youth expressed a strong desire for independence and yet they lacked the experience, skills or emotional stability to get or keep a job and to manage their own finances. Many of the youth wanted friends and a relationship, but few had any friends and spent the majority of their time isolated at home with their families. More than anything, youth said that they wanted to be like other people their age and they did not want to be treated differently by having to participate in programs and follow rules. Most youth wanted to live on their own in an apartment with access to transportation.

Employment was a major concern; youth who did obtain employment often were not able to keep their jobs due to absence or poor performance. In general, if employed, youth were in low paying jobs that did not provide benefits or a sufficient income that would support living independently. Despite the hurdles they had encountered, all youth participants had career aspirations that they felt they could accomplish – with the right help.

While many youth were very intelligent, there was a significant gap between their cognitive development and their social and emotional development. The gap impeded their ability to interact with others, establish social relationships and perform daily living skills, such as money management.

Families expressed frustration that when their children turned 18, parents were not legally permitted to be involved in their children's treatment. While understanding their children's need for independence, families felt that they needed to have input with providers and have access to certain information such as medications. In times of crisis, families are the ones always called upon and therefore they should be aware of critical information.

POLICY AND SYSTEMS RECOMMENDATIONS

Based on the feed-back the Coalition received from families and youth in the focus groups, and drawing on our experiences with successful policies and programs for children and adolescents with mental health needs, the Coalition makes these general recommendations:

1. Align the Definition of Transition-age Youth Across State Agencies

Presently, state agencies define the age boundaries of transition differently. Some agencies terminate services when a youth turns 18, while other agencies continue to serve youth through age 21. These differing age distinctions pose barriers to eligibility and create major gaps in serving transition-age youth. The state should align the definition of transition-age youth across agencies and consider raising the transition age to 24, which coincides more accurately with the social and developmental needs of transition-age youth.

2. Build a System of Care for Transition-age Youth with Mental Health Needs

Over the past decade there has been a concerted effort to build systems of care for children and adolescents with mental health needs and their families. The distinguishing difference between building a system of care rather than simply developing services is that a system of care incorporates a broad array of services and supports organized into a coordinated network. A system of care also integrates care planning and management across multiple levels, is culturally and linguistically competent, and builds meaningful partnerships with families and youth at service delivery and policy levels.[ii] The state should move to the concept of building a system of care specifically designed to serve transition-age youth, addressing the following components below:

a. A Family-driven and Youth-guided System

Consistent with the President's New Freedom Commission goals, the system of care for transition-age youth should involve youth and their families in planning, implementation and evaluation of transition-age services and systems. Principles of a family-driven and youth-guided system of care have been adopted by SAMHSA; these principles should guide the state in the development of a transition-age youth system of care.

b. An Individualized Approach

There is a wide range of social skills and levels of functioning among transition-age youth, therefore services must be individualized. Many of the youth voiced their opposition to having to participate in a "program" because it did not meet their needs or because they felt it was stigmatizing. The state has invested in developing a System of Care using a wraparound approach for children and adolescents with mental health needs. This individualized approach could be expanded to serve the population of transition-age youth with mental health needs.

c. A Model for Serving Transition-age Youth

Transition-age youth are a unique population with special needs. While young adults are no longer eligible for the child and adolescent system, their needs do not fit the traditional adult system of care either. Several national models for serving transition-age youth have been developed, such as the Transition to Independence Process (TIP). Various models should be explored and, with input from families and youth, the state should adopt a model to strategically begin building a transition-age youth system of care.

d. Funding for Vocational, Educational and Residential Services

Currently the Mental Hygiene Administration provides funding for eleven TAY programs across the state. Most serve a very small number of youth. The eligibility criteria and the services provided vary tremendously among jurisdictions. The number of programs and the capacity of existing programs have not expanded since their inception. The Mental Hygiene Administration should review current programs, evaluate their effectiveness and consistency with the state's system of care principles.

The Bazelon Center for Mental Health Law has identified 57 federal programs for transition-age youth that are run by 20 or more different agencies in nine departments of the federal government. The state should explore all options to secure funding from all sources to expand vocational, educational, transportation and residential services.

e. Interagency Coordination

Services for transition-age youth are provided by numerous agencies. The Mental Hygiene Administration should take the lead in ensuring that all agencies are attuned to the special needs of youth with mental health needs and that all agencies are equipped to serve this population appropriately. This coordination is particularly important for youth with co-occurring disorders including mental health and substance abuse, as well as mental health and developmental disabilities.

3. Organizational Structure

The Mental Hygiene Administration should assess the most effective organizational structure for transition services within the Administration. This could mean creating a new division for transition-age youth within the Mental Hygiene Administration, moving transition services to the Child and Adolescent Services Division or keeping transition-age youth services within the Adult Services Division. There are advantages and disadvantages to each of these structures. It would be useful to explore all possibilities to determine which structure would prove most beneficial to the transition age population.

4. Youth Advisory Council

The Mental Hygiene Administration should develop a youth advisory council to provide input into services and supports for transition-age youth.

5. Health Care Coverage

In order for youth with mental health needs to successfully transition to adulthood, it is critical that they continue to receive health care benefits so that they can continue with their medication and treatment plans. Yet this population is highly unlikely to have access to health care coverage. There are a number of measures that the state can take to ensure that more transition-age youth with mental health needs have health care coverage:

a. Medicaid

Allow low-income youth to qualify for Medicaid until age 21. In 2001, the federal government allowed states to raise the age limit for Medicaid eligibility to age 21.

b. MCHIP

Expand the MCHIP program to cover youth to age 24. A sliding fee scale could be implemented so that youth could contribute to their coverage, and this would offset some of the cost to the state.

c. Private Insurance

Enact legislation that requires that insurers allow parents to opt to extend the coverage of their children up to age 24.

6. Evaluation/Effectiveness

An ongoing evaluation process should be developed to evaluate the effectiveness of programs and track outcomes for youth who are served in TAY programs.

RECOMMENDATIONS FROM FAMILIES AND YOUNG ADULTS

In the focus groups held by the Coalition, families and youth presented a number of specific recommendations about how to better assist youth with mental health needs and their families with transitioning to adulthood. They identified a number of critical areas:

Transition Preparation

1. Families and youth need an identified place to get information about transition services and supports. This includes guidance on applying for benefits, housing, educational and employment options. While IEPs address transition and many local school districts hold educational evenings for families and youth leaving school, families were asking for much more. Families need a specialist with a mental health perspective to help them and their children map out individualized transition plans.
2. Providers, Core Service Agencies (CSAs) and family organizations should provide educational programs to help families understand their changing roles as youth transition to adulthood. Families have been lifelong advocates for their children through school and have been closely involved with their children's mental health treatment. Learning to let go can be difficult and frightening for families. Families repeatedly expressed concern that they knew they needed to step back, but didn't know when or how.

"In 11th grade, the school made all the referrals. In his senior year, he started with DORS. He graduated and has a job, a mentor once a week and a social skills group run by a therapist." - A Mother

"Once he graduated from high school, the linkages were gone. What do we do now?" - **A Mother**

Housing

1. There is a desperate need for more housing options for transition-age youth. Family members felt that there should be a spectrum of supported housing services available – from Section 8 rental vouchers for independent living to 24/7 care in a more structured environment. Many families felt hopeless about the possibility that their children would ever be able to move to an independent living situation because options are so limited and waiting lists are so long.
2. Staff members working in transition-age youth (TAY) programs need training on the unique needs of this population, and staff should have close supervision. Both adults and youth agreed that staff competency and absenteeism were problems. Youth also expressed frustration that staff did not know how to relate to their age group and often treated them as children.

3. Housing should be located near public transportation to foster independence and access to employment.
4. TAY programs should maintain a home-like atmosphere with youth having input into the house rules. Many youth participants (but not all) disliked the idea of having to live in supported housing where there was staff oversight and rules. Youth were unanimous, however, in their opinion that supported housing should look and feel like "their home," and not like they are clients in an institution.

"My child needs more than support for rent – he needs case management, a mentor and a whole spectrum of services." **A Mother**

"Having the chance to be on his own has taught him so much over the last year." **– A Mother**

Employment

1. More employment services are needed - such as job coaches, mentors, job placement and supported employment - to help youth transition to competitive employment. Families reported that their children's high intellectual abilities were deceptive because their children lacked the social/emotional skills necessary to interact with customers and co-workers.
2. Access to public transportation is critical to employment. Adults and youth agreed that transportation was among the greatest barriers to successful employment. Lack of transportation limited job options; most youth had neither a driver's license nor a car, and since their housing options were extremely limited, few had access to public transportation. Some youth were driven to work by their parents, others paid cab fares, which took up a large chunk of their salary.
3. Vocational programs should adopt policies that are more sensitive to the needs of youth with mental health needs. Families often felt their children's level of intelligence was an impediment to accessing appropriate services.
4. Programs should assist youth to identify and achieve career goals and earn a living wage. Families and youth repeatedly expressed frustration that the only jobs youth were encouraged to take were low paying jobs with no opportunity for benefits or career advancement.

"These kids need meaningful career oriented jobs." **–A Mother**

"*They couldn't find anything appropriate. I created a job for my daughter."* – A father

Where Are the Young Adults Working?

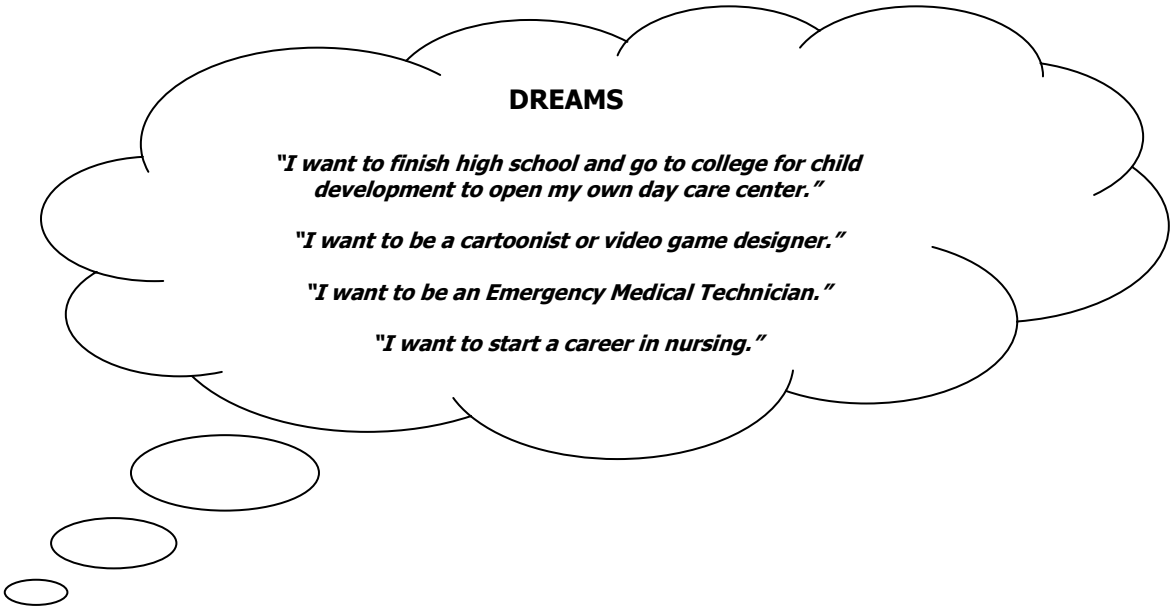
- ✓ Fast food
- ✓ Summer camp
- ✓ Shoveling snow
- ✓ Bank teller
- ✓ Auto detailing
- ✓ Pharmacy tech
- ✓ Bussing tables
- ✓ Construction
- ✓ Landscaping

High School and Post High School Education

1. High Schools should work closely with youth before graduation (or certificate completion) to provide advice about options available after graduation.
2. Non-public schools should coordinate with local school jurisdictions to develop transition plans for youth graduating from a non-public school placement.
3. Community Colleges should develop services, supports and accommodations to serve young adults with mental health needs.

"IEPs were not helpful – just very frustrating." - **A Young Adult**

"When I went to the community college, I felt my life expand. I had something to wake for in the morning." **– A Young Adult**



Life Skills: Banking, Budgeting, Shopping, Cooking and Social Life

1. Life-skills classes and mentors should be a component of all TAY programs and should also be available for youth who are not participating in a TAY program but could benefit from life skills coaching.
2. TAY programs and CSAs need to address the wide range of social skills among transition-age youth. Group participants tended to fall into two camps – youth who felt they had a very normal social life – they had friends and "liked to party." Some admitted that they used drugs. Other youth were silent about their social lives. Instead, many family members spoke of their children's isolation, lack of friends, and intense loneliness. They felt their children needed somewhat enforced group activities and social skills groups. TAY programs should be equipped to provide structured, affordable, and age appropriate socialization opportunities for youth who need socialization skills, as well as to closely supervise those youth who might engage in risky behavior.

"I have a boyfriend and I like to party." – **A Young Adult**

"Our children need to learn the difference between living with people instead of living around people." **- A Mother**

Mental Health Treatment

1. Families should be informed about medical power of attorney and encouraged to discuss this option with their children. Families should be informed of legal resources to obtain medical power of attorney at low cost.
2. At the treatment level, parents must be part of the treatment planning process when the youth believes them to be an essential part of the team. While there may be legal complexities to parental involvement in an adult child's treatment, it is clearly necessary to include parents as much as possible and for their participation to be considered important to the child's well-being.[iii]

***"He's non-compliant with meds and then 'crashes out' for months and goes on suicide watch."* –A Mother and Father with a Son Living at Home**

"I have no legal authority to know what is going on in my child's therapy, yet we are paying for all of his living expenses, housing, everything." – A Mother

CHALLENGES

Several families spoke of unique challenges they faced with their child:

- Programs that serve Co-occurring disorders - mental health and substance abuse as well as mental health and developmental disabilities
- Young adults who are also parents
- Non-English speaking families.

VOICES OF FAMILIES AND YOUNG ADULTS

The following pages contain quotes from mothers, fathers, foster families and youth who participated in the groups. The quotes are grouped around issues raised during the groups. Their words are honest, painful and passionate.

Housing and Housing Programs

"I want to live independently – in my own apartment located where I can get around on my own." –A Young Adult

"It's embarrassing to have friends over. I don't want anyone to know I live in a group home. Like I'm stupid and can't live with my family." - A Young Adult

"They basically say here's the program, take it or leave it." –A Young Adult

"My child is living pillar to post. He can't rent a room since he has no credit history." –A Mother

"They need low-income housing or some form of rental assistance because our youth can't afford housing on their pay." Many Mothers and Fathers

"Housing programs won't accept them with co-occurring disorders." -A Mother

"The group home is in the middle of nowhere, it's so hard to get out." –A Young Adult

Program Staffing

"They need to understand we are young men. (They) don't see anything from my point of view." –A Young Adult

"Staffing needs to be consistent with sufficient coverage and competent, trained people." –A Mother

"Funding is so low, they're hiring the wrong people but it's the only people they can get." –A Father

Employment

"My daughter needs pre-employment training." –A Mother

"Transportation is the toughest issue for employment. Parents end up driving." – A Father

"They don't even know when they aren't doing well in their job." –A Mother

"Parents sometimes have to intervene with the employer." –A Mother

"They need coaches and mentors to help with practical skills such as getting a job and budgeting money. Coaches could also assist with setting and achieving goals." –A Mother

"We decided to forego DORS' help because of their low expectations, labeling and preconceived notions about where my son should be employed and what he could not attain." - A Mother

High School and Post High School Education

"Youth sabotage graduation because they are afraid" –A Foster Mother

"My son graduated before I knew it. I thought he could stay until he was 21. How was I to know?" –A Mother

"The non-public school didn't tell me anything. It can be more difficult to find out about DORS and other services for transition-age youth when your child graduates from a non-public." –A Mother

Life Skills - banking, budgeting, shopping, and cooking

"(They) need after school activities that train youth on life skills such as money management." –A Mother

"These kids really need living skills classes. Many of them are bright, but they have delayed social/emotional development. –A Parent

Social Life

"He is very isolated. It's important for him to be with typical peers." –A Mother

"She doesn't identify with others who have disabilities." –A Mother

"My child wants to fit in – he doesn't want to be singled out." – A Mother

"Karate works. No therapist has come close." –A Foster Mother

"Social life is the most important thing that would make a difference, but that is where the void is." – A Father

"They have such a low self-esteem that they are afraid to reach out to other people, and they have very limited social skills." –A Parent

Health Coverage

"Young Adults *without* the problems of our kids can't find a job that offers private insurance. Our kids probably will never find this. But they need medications for the rest of their lives. The kids stop taking their medications because they can't afford them." – A Father

"My son will be forced to choose between being stuck in a low paying job just so that he doesn't lose MA coverage and access to services." – A Mother

Benefits: SSI and Medical Assistance

"Families are not told to apply for SSI benefits before their child turns 18."
-A mother

"My son's on SSI and says he doesn't need to work. He had to realize that there is more to life than lying on the couch and sleeping to noon." –A Mother

"With the cost of meds, I had to wean the kids off of meds because they lose their MA card when they turn 18 years." – A Foster Mother

"My son did well in high school and fell apart in college. He had private insurance and is not eligible for Medical Assistance." –A Mother

Family Involvement

"I retired to care for my daughter." –A Father

"He refuses to take his meds or go to therapy." –A Mother

"I need respite care." –A Mother

"I have hope and optimism – but I feel I need to stay nearby to pick up the pieces." – A Mother

ABOUT THE COALITION

The Maryland Coalition of Families for Children's Mental Health is a grassroots coalition of family and advocacy organizations dedicated to:

- Improving services for children with mental health needs and their families
- Building a network of information and support for families across Maryland.

The Coalition represents families across Maryland who are caring for a child with mental health needs. Many children have been in a psychiatric hospital, residential treatment center, juvenile justice facility, or special education program.

Each family struggles to find appropriate services for their child and many families face staggering costs for treatment and other special services their child may need.

Even with the challenges of raising a child with serious emotional or behavioral needs, families have strengths and want to be full partners with professionals in planning for their child's treatment and care.

We Believe

- Children with mental health needs have potential and require specialized services to achieve their full potential.
- Families are the constant in a child's life and are equal partners in planning, implementation and evaluation of services for their child.
- Services should be provided for children and families from a strength-based approach and consider the whole child and entire family.
- Communities should develop a coordinated system of care that is available to all children with mental health needs and their families.

We Offer

- One-to-one information, support and advocacy to families caring for a child with mental health needs
- Advocacy training for families through the Family Leadership Institute
- Sibshops for children who have a brother or sister with mental health needs
- E-newsletter
- Publications

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NOTES

[i] Clark, H.B., p.5.

[ii] Pires, Sheila, (2002) Building Systems of Care – A Primer, p.3.

[iii] Service Systems Supports During Transition from Adolescence to Adulthood: Parent Perspectives, June 2002, National Technical Assistance Center for State Health Planning, p.x.

APPENDIX A

Participant Data

Both adults and youth participants completed information sheets at the end of each group. Table 1. summarizes data from the collected from the information sheets.

Table 1. Data Completed by Parent/Caregiver Describing Youth in Their Care

Total Number of Youth/ Young Adults	**40**	**100%**
Male	23	58%
Female	17	42%
Ages: 15-25 yrs		Mean = 18.4 years Median = 17.5 years
Education of youth		
Public schools	22	55%
Non-public	16	40%
Residential program	15	37% Range = 6 mos. to 11 yrs. Mean = 4 yrs. Median = 3.5 yrs.
Graduated or expect to graduate	24	60%
Dropped out	6	15%
Mental Health		
Therapy	40	100%
Medication	38	95%
Hospitalization for psychiatric treatment	26	65% Mean = 6 hospitalizations Median = 3.3
Employment		
Presently working	11	28%
Needs supported employment	26	65%
Being served by DORS	8	20%
Health Care/Benefits		
Receiving SSI	12	30%
Turned down for SSI	4	10%
Receiving MA	30	75%
Family's private insurance	21	53%
Living Arrangements		
With family or foster family	26	65%
Independently	2	5%
Supported living including TAY Program	14	35%
Homeless	3	8%

Note: Some participants did not complete all items on the data collection sheet, so not all categories add up to 100%.

Table 2. Data Completed by Youth/Young Adults

Total Number of Youth/ Young Adults	**33**	**100%**
Male	22	67%
Female	11	33%
Ages: 15-25 yrs		Median age 17 years
Education of youth		
Public schools	17	51%
Non-public	10	30%
Residential program	14	Range = 6 mos. To 15 yrs. Avg. LOS 4.5 yrs
Graduated or expect to graduate	15	45%
Dropped out	6	18%
Mental Health		
Therapy	33	100%
Medication	30	91%
Hospitalization for psychiatric treatment	17	51% Avg. # of hospitalizations = 6.2
Employment		
Presently working	7	21%
Needs supported employment	16	48%
Being served by DORS	5	15%
Health Care/Benefits		
Receiving SSI	11	33%
Turned down for SSI	3	
Receiving MA	29	88%
Family's private insurance	13	39%
Living Arrangements		
With family or foster family	21	63%
Independently	3	9%
Supported living or Tay Program	7	21%
Homeless	2	6%

Note: Some participants did not complete all items on the data collection sheet, so not all categories add up to 100%.